Risk as a relational phenomenon: a cross-cultural analysis of parents' understandings of child food allergy and risk management

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Marie-Louise Stjerna[a]*, Allison Worth[b], Jeni Harden[c] and Sonja Olin Laurtizen[d]

[a] School of Culture and Education, Södertörn University, Huddinge, Sweden, [b] Edinburgh Clinical Research Facility, University of Edinburgh, United Kingdom, [c]Usher Institute of Population Health Sciences and Informatics, University of Edinburgh, Edinburgh, United Kingdom and [d]Department of Education, Stockholm University, Department of Education, 106 91, Stockholm, Sweden.

* **Corresponding author:** Marie-Louise Stjerna Email: marielouise.stjerna@sh.se

Short title: Risk as a relational phenomenon

Abstract

Western culture can be seen as permeated by risk-consciousness. In particular, parents are under scrutiny in their roles as risk managers. In this article, we address parental experiences of children more at risk than others, children with food allergy, and the management of allergy risk in everyday life. Drawing on a notion of risk as 'situated' in local everyday life, we argue that a further exploration of parental understandings of child food allergy risk would benefit from an analysis of studies across different local contexts. In this article we draw on a

secondary qualitative cross-cultural analysis of interview data from several studies of parents in Sweden and Scotland through 2006-10, which focussed on parents' understandings of the nature of food allergy and the children's management of the allergy risk. We found some common themes in the different data sets. *First,* food allergy was depicted as life-threatening, a 'death risk' lurking in the background, more or less constantly present in different everyday situations, amounting to an existential condition in parenting. *Second,* food allergy risk was seen as a relational phenomenon, meaning that the risk emerged in the encounter between the young person's individual competence to manage allergy risk and the understandings of allergy risk in others – thus depending on contexts and interaction between several actors. These aspects of food allergy were discussed in terms of unpredictability and risk in constant flux, the ways risk and trust were related as well as how the involvement of others could be seen as a risk *and* a safeguard.

***Keywords*:** risk, everyday life, parents' understandings, child food allergy, secondary qualitative cross-cultural analysis

Introduction

The overall purpose in this article is to contribute to research on risk in everyday life by exploring parents' experiences of living with a child that is constantly at risk due to a serious condition; in this case child food allergy. Western culture can be seen as permeated by risk-consciousness and may even be described as a 'culture of anxiety'. In particular, parents are under scrutiny in their roles as risk managers (Furedi, 2001; Pain, 2006). As Lee et al. (2010) put it: 'No child, it seems, is now considered to be 'safe' (2010, p. 295). Life-style risks are related to different sorts of consumption, and 'good' parenting means to conform to public

health imperatives such as controlling children's food consumption (Keenan & Stapleton, 2010) and limiting sedentary time (Bonke & Greve, 2012). As Lee et al., (2010) argue, mothers often seek to show that they are risk-conscious when explaining their actions or experiences in relationship to their children (Lee at al., 2010). At the same time 'wrapping children in cotton-wool' is seen as highly undesirable (Jenkins, 2006; Layard & Dunne, 2009).

This contemporary emphasis on risk raises questions about the experiences of parents living with children who can be deemed more 'at risk' than others. As parents are mediators of children's health and well-being it is important to explore more in-depth their understandings of the challenges and constraints their children face in everyday life, particularly as parents will act on these understandings in supporting their children in the management of the condition. Previous studies of parents of children with food allergy have demonstrated that risk management to avoid the 'dangerous food' does affect the day to day lives of the family in many ways. However, these studies have predominantly been small scale qualitative studies conducted in local areas, and we would argue that a broader analysis across different socio-cultural contexts can further our knowledge about parents' experiences of the risks involved in child food allergy. In this paper we will present a secondary analysis of several studies of parents of children with serious food allergy carried out in Scotland and Sweden.

Parenting, risk and food allergies

Parents' experiences of child food allergy

Food allergy affects life on a daily basis in profound ways as it is related to food and eating, and can involve severe and even life-threatening reactions. The most common food allergies are to milk-protein, egg and nuts (Arias et al., 2009) but the list of potential food allergens is

much longer. Currently there is no cure or preventive treatment, and food allergy therefore requires constant vigilance to avoid the allergen(s). In addition to a constant vigilance, the allergic individual also has to be constantly prepared *if* something should happen. Children with risk of severe allergic reactions should carry an adrenaline injector at all the time. (Simons, 2010). In the Western world, child food allergy is considered a growing public health issue, today affecting up to 12 % of the child population, depending on definition (Burks et al., 2012). There is also evidence that this condition is likely to increase globally in the coming decade (Prescott et al., 2013).

Empirical studies have demonstrated that parents of children with food allergy seem to share the experiences of 'living with risk and fear' (Gillespie et al., 2007; Rouf et al., 2013; Cummings et al., 2010). Parents often experience a high degree of anxiety when their child receives a food allergy diagnosis (Klinnert and Robinson, 2008). However in some cases, parents continue to be very worried even when some time has passed and may adopt far-reaching measures to protect their children which can limit the child's social activities and have an impact on the child's social development and transition to adult life (Bollinger, 2006; Klinnert & Robinson, 2008; Fenton et al., 2013). Researchers have also found that children and their families feel burdened by a variety of tasks in everyday life, such as careful food label reading, adaption of recipes and that eating away from home is associated with difficulties (see Avery et al., 2003; Gallagher et al., 2012). Parents also told researchers about their worries about handing over the main responsibility for allergen avoidance to their children (Akeson et al., 2007) and researchers have identified parents' and food allergic teenagers' varying understandings of the risk of life-threatening anaphylaxis (Mandell et al., 2005; Akeson et al., 2007; Gallagher et al., 2011, 2012). Furthermore, parents have to educate others to take precautions to protect their children, and the 'disguised' character of

food allergy – as it is visible only when the child has an allergic reaction – makes risk management in communication with others an even more challenging task for parents and children (Stjerna et al., 2014).

A socio-cultural perspective on food allergy risk

To explore parents' understandings of child food allergy risk we are drawing on an approach to risk as a social phenomenon dependent on context and culture (see Douglas, 1992; Boholm, 2009, 2011; Zinn, 2008, 2009) with different 'logics of risk' existing in different historical and socio-cultural contexts, situations and between individuals (Tulloch and Lupton, 2003). According to this perspective, the ways people understand various aspects of risk as related to health and illness can be seen as developed in communicative and interactive processes within social and cultural contexts drawing on resources such as medical expertise, media as well as family and friends networks (Jovchelovitch 2007). This means that risk also can take on more implicit and even contrasting meanings that can underpin people's concerns about health and illness (Markovà 2003). In this perspective, parental risk constructions are understood as embedded in values, lifestyles and everyday practices, as 'situated' risk (Henwood et al., 2008).

When it comes to issues of food and risk, it is argued that food has become profoundly medicalised in its association with health and illness, and there is also a growing focus on how consumption of food is related to risk. The development of notions of 'good' and 'bad' food is shaped by contradictory advice from expertise (Beck 1992, Giddens 1991). Typically, food consumption is habitual and routine. It is only when something out of the ordinary happens, such as an outbreak of salmonella or BSE (that can be seen as archetypical food scares) that people change their daily food consumption behaviour, at least for a certain

time (Green et al. 2003). However, unlike the consumer in general, who 'during normal food-related behaviour… is fairly unlikely to suffer from the potential hazards (e. g. food poisoning)' (Fisher and De Vries 2008 2008:388), food consumption involves serious risks to people with food allergies.

The development of increased public health information on food risks and benefits in high income countries has been associated with the view that it is the individual's responsibility to identify and avoid risk through appropriate life-style choices, particularly in terms of food choices and other types of consumption (Lupton 2000). Thus there is an expectation that as children and young people with food allergy grow older and have access to appropriate risk information they will take increasing responsibility for managing the risks of their allergy. However to do this they need to continuously assess whether their food is 'allergy safe', while dealing with the social pressures to engage in social activities that expose them to risks.

Risk-consciousness is a powerful part of contemporary parenting culture and parenting a child with food allergy adds specific challenges related to food consumption as children with food allergy are faced with risks in consuming food that is unsafe for them but not to other people. In this article we examine parental understandings of child food allergy risk and how this risk is situated in local everyday life by presenting a secondary analysis of data from several studies across different local contexts. Specifically we examine:

- parents' understandings of the nature of child food allergy risk
- parents' understandings of the child's management of food allergy risk in everyday life

Methods

Given the notion of risk as situated and embedded in local lifestyles and everyday practices, a further exploration of parental understandings of the nature of child food allergy and the ways the child manages food allergy risk, would benefit from an analysis of studies carried out in different local contexts. Following contacts and discussions between the authors of this paper, we found that we had been involved in studies on parental experiences of child food allergy in Scotland and Sweden, with similar overall purposes and methodological approaches. These existing data-sets provided an opportunity to study parental responses to food allergies in Scotland and Sweden using data from different local socio-cultural contexts.

The purpose of our secondary analysis was not to compare the two countries, but to draw on the range of available material in a secondary analysis. The Swedish and Scottish data is interesting as both are northern European countries with many similarities, not least in terms of food allergy trends and health care services. As in other north European countries, food allergy is seen as a major public health issue; allergy to most foods, except soy and peanut is more common in Northern Europe than other European regions (Nwaru et al., 2014). There are also debates about how to ensure, throughout Europe, equitable provision of the expertise of allergologists, who in collaboration with other health care professionals take care of patients with food allergy (de Monchy et al., 2013). Further, in both Sweden and Scotland, there are patient organisations addressing the needs of the growing number of people with allergies.

Data sets

In this article we draw on two existing comprehensive data sets, one from a study in Sweden and the other from three studies in Scotland in 2006-10. The two data sets consist of

interview data from focus groups, workshops, interviews with couples and individual parents. The Swedish and Scottish materials were collected independently, but are comparable as both:

- included qualitative interview data with parents of children with food allergy
- addressed similar interview themes
- were collected during approximately the same period of time

Table 1 about here

The Swedish data were collected in 2009 and include ten focus group interviews on the everyday management of the allergy at home, preschool, school and other arenas with 31 parents of children with food allergy, 25 mothers and six fathers of children aged one to 17 years who were recruited through two children's hospitals in Stockholm. The parents were native Swedish speaking, with a level of education varying from upper-secondary school to university, living in an urban area. All children had been diagnosed with a food allergy, either single food or multiple, varying from mild to potentially life threatening allergy, and most of them were prescribed an adrenaline autoinjector (Stjerna et al., 2014). In addition, individual interviews were carried out with two fathers and five mothers who had participated in the focus groups to shed light on meanings of the child's allergy risk in the family's life over time. The study was approved by the Ethics Committee at the Karolinska Institutet (Nr: 2008/569-31, 2012/1051/32)

The Scottish data consist of data from three studies. In 2006 one interview with a couple and six individual interviews were carried out with parents of food allergic adolescents (13-

19 years old), diagnosed with anaphylaxis and living in the South of Scotland. Participants were recruited via a patient support group and primary care (approved by Lothian REC3 ref: 06/S1103/14) (Akeson et al., 2007). In 2008 three interviews with couples and 18 individual interviews were carried out with parents of adolescents (13-19 years) with a history of anaphylaxis. The parents were recruited through school nurses, specialists, primary care, a patient support organisation and via a press release from locations across Scotland (approved by Fife, Forth Valley and Tayside REC ref: 08/SO501/24) (Gallagher et al., 2011, 2012). In 2009 one focus group and two workshops were carried out with parents of children from primary school age to adolescence, with a confirmed diagnosis of anaphylaxis and attending school in the Lothian region (approved by Lothian REC2 ref: 08/S1102/38).The workshops involved feeding back preliminary findings from interviews with young people and their parents to participants who then prioritised the actions they thought health services, education and policy makers should take to improve allergy care. Topic guides for all studies addressed certain key themes: the young person's history of anaphylaxis, issues around transition to adolescence, risk assessment, social impact, support and treatment. All studies were thus approved by Research Ethics Committees in Scotland.

The children in both data sets, from pre-school children to teenagers, had been medically diagnosed with food allergy (in contrast to self-reported allergies), and most of them had been prescribed with an adrenaline injector and/or had a history of anaphylaxis – and thus had severe food allergies. Both data-sets comprise interviews with parents with different socio-economic backgrounds and in the Scottish data from different regions. The Swedish data were collected in an urban area and the Scottish data were collected in urban and semi-rural areas. Together these two data-sets constitute varied, comprehensive and rich

interview material which offers a solid ground to do a qualitative secondary cross-cultural analysis.

Ethical considerations

The purpose of the analysis presented in this article is to utilise available data collected within several small scale qualitative studies in Scotland and Sweden in order to add a broader empirical variation across socio-cultural contexts to the analysis - and thus further our knowledge about parental experiences of risk management beyond the local context.

All studies had been approved by Research Ethics Committees before being carried out in 2006-10. In each study, participants had given their informed consent to participate in a study of parental experiences of child food allergy, which is also the purpose of this secondary analysis. The material from all interview studies was already transcribed verbatim and anonymised before this secondary analysis took place. This analysis is based only on the anonymised material, and no other information about the individual participants was used by the researchers. As the researchers who carried out the secondary analysis are the same as in the individual studies, as are the overall purposes and methods, this secondary analysis can thus be seen as another step in a qualitative research process.

A cross-cultural secondary analysis of qualitative interviews

The aim of the qualitative cross-cultural secondary analysis was to identify and analyse thematic similarities and variation in the data (Irwin et al., 2012; Bishop et al., 2007), by returning to the collected material in both data-sets and carrying out a thematic analysis. Such analytical comparisons have proved to be productive in earlier empirical studies of parenting and child care practices (see Olin Lauritzen, 1997). In this study, the first author

(Marie-Louise Stjerna), who had collected and analysed the primary Swedish data, carried out the secondary analysis of the two data sets in collaboration with the Swedish team member (Sonja Olin Laurtizen) as well as with the members of the Scottish team (Allison Worth and Jeni Harden). When doing the secondary analysis, Marie-Louise Stjerna had access to the entire transcribed Scottish material, as well as the transcribed Swedish material, and discussed the steps in the analysis with the other team members. Marie-Louise Stjerna thus had a first-hand inside perspective of the Swedish material, of 'being there' plus the benefit of being familiar with the Swedish food allergy field. The lack of the same experience of Scottish data was balanced by the contact with the Scottish researchers.

The analysis of the two data sets was carried out in several steps. First, the Swedish and the Scottish data were analysed separately but addressing the key questions concerning parents' understandings of the nature of food allergies and their perception of their child's management of the food allergy. This was done by categorising the data into topics discussed by the parents drawing boundaries between topical episodes that are held together internally as the participant(s) discussed or accounted for a certain topic during a sequence of time (Markovà et al., 2007). Second, these categories were compared within and between the two sets of data in terms of similarities and differences in the ways parents talk about their children as being 'at risk'. In this second step, the analysis revealed two major underlying themes that dominated the parents' discussions within but also across the two data sets, themes that we will address in this paper: the life-threatening aspects of food allergy and risk as a relational phenomenon.

Findings

The first aspect of risk that emerges from the analysis, is a powerful notion of the nature of child food allergy as life threatening, something that seems to be fundamental to parents in both countries, across different local contexts.

The life-threatening aspects of food allergy

The parents in the studies largely talked about food allergy risk as a 'death allergy' or a 'death risk'– and in this sense different from other allergies. We found that parents claimed that there are common existential experiences that parents of children with food allergy share, which should be communicated to a wider public to gain a better understanding of the lives of these families. This notion of food allergy risk dominates in the two data sets, albeit depicted in different ways using examples from different everyday situations and with some variation in the seriousness of the risk. The following quote is from a Scottish mother talking about food allergy as a 'death allergy':

> Allergies are in many cases considered as people just being awkward or using their allergy for attention and so even to have it re-named I think would be valuable, you know death allergies. No let's… we can't be too dramatic about this because that what it is and that's what the people are living with. They're not living with their child having a wee moan if they touch a cat, they're living with the possibility of that child dying. (Paired interview, Scotland)

This mother stressed the seriousness of the condition and made comparisons with other types of allergies that are very different, and might amount to the child just having a 'wee moan'. Similarly, in the following quote from a Swedish mother, food allergy is talked about as a 'death risk':

> It is the death risk that is around, I think that is really tough, and still you all the time have to see too that he goes off anyway, he is going to Italy for his confirmation and of course he should participate in everything, life has to go on, but as a parent you are anxious. (Focus group, Sweden)

While many parents emphasised the severe or life-threatening aspect of the food allergy risk, there is some variation, amongst the participants in the different studies, in how they talked about the degree of danger. There are numerous examples of how parents recognised the life-threatening risk but some parents dwelled even more on and commented on those aspects. These parents returned repeatedly to the risk that the child *might* have a life-threatening reaction and some of them recalled dramatic incidents when their child did have an allergic reaction. One Scottish mother described how the allergic reaction escalated within minutes and required medical care (all names in excerpts are psuedonyms):

> I was explaining about April's breathing [via telephone to emergency care] and the lips going blue and it ended up there were two sets of emergency services had come into the room and asked how much of the adrenaline she'd took. (Individual interview, Scotland).

Less common in both data sets are parents who talk about allergy risk management as not such a big issue in their lives. In this focus group discussion, a Swedish father compared his daughter's allergy with that of other children:

> Compared with many, with you [who have children allergic to milk-protein] I don't think it is so difficult, so that's why I am a bit quiet, because we really just have Klara's eggs, and nuts are definitely not difficult for us to avoid, we have never had any problems with that. (Focus group, Sweden)

Through the interviews, parents talked about their children becoming more aware of the severity of their allergy as they grow older. At the same time, some also expressed fear of what could happen if the child did not remember having had any severe allergic reaction, and therefore not taking the allergy risk as seriously as he or she should. A Scottish father explained that remembering having had a severe reaction may alert his two sons to the allergy risk:

> They're not silly enough to go out and say right we'll have that and see what happens because they both have had to them a bad reaction and they both for whatever times it happened they got quite upset about it. (Paired interview, Scotland)

Parents also reported concerns about how to communicate the life-threatening potential of food allergy with their children. Specifically, as this quote by a Swedish mother illustrates, parents expressed difficulty in finding a balance between ensuring that their children were aware of the severity of the risk, yet at the same time not scaring them too much:

> I have noticed that Oliver, even though I try to keep my worries to myself, I really work hard to keep him happy and so, because I think it is not right to convey your own worries, but I think he has a death fear due to all these experiences [of severe allergic reactions]. (Focus group, Sweden)

In both data sets, the life-threatening aspect of food allergy was also talked about in terms of the impact this has on how parents and children organised and managed daily life. One example is a Swedish mother who explained that on holiday she always finds out where the

nearest hospital is, in case of an acute allergic reaction. Eating out is regarded as particularly risky. Parents' accounts highlighted that even when restaurant staff are informed about a child's allergy, they do not trust that it is taken seriously:

> that worked fine, he [the waiter] knew the level of the problem, he thought he was honest in saying we, there's no butter in the place and if there's any oil on that it's going to be olive oil and we don't cook anything with nuts or anything in it. So that, we [this mother and her teenage daughter] discussed it and took that kind of risk. But it does take the pleasure out of eating out, when you have to, when it's a game of Russian roulette every time you do go out (Individual interview, Scotland).

This excerpt illustrates the experience of having to take a risk, here described as 'a game of Russian roulette' when eating out. Again, the risk management is part of the everyday lives of the children with food allergy and their parents, and it is ultimately they themselves who have to decide whether to take a risk or not. Another arena of food allergy risk management highlighted by parents in both data sets is the school. Parents have to make sure that the school has implemented a food allergy policy, and that every teacher knows about the child's allergy. This Scottish mother talked about her fears when the regular teacher, who knows about her son's allergy, is not around: 'You know sometimes, when I go and I see at the door that it's not his teacher I go home and I can hardly concentrate just with fear' (Focus group, Scotland).

Across the two data sets the parents, in different ways, emphasised the life threatening nature of their children's food allergies. Altogether this says something essential about parents' understandings of the fundamental characteristics of food allergy, a threat of a

severe even life-threatening reaction, that is always there, not possible to escape in spite of precautions. Even if the parents across the Swedish and Scottish data sets recognised the life-threatening allergy risk, there is a variation in their accounts, predominantly related to their understandings of the degree of danger. Whilst dwelling on the severity and the life-threatening aspect of the condition, there are also accounts of how they are able to 'live with it', and some accounts of not experiencing the allergy risk as such a 'big deal' – they can handle it. However, this variation does not seem to be related to any specific local contexts, but rather to how parents understand the condition per se and the health of the individual child. Also, the parents made comparisons – such as 'my child's allergy is not as bad as other children's food allergies' – as a way of finding a balance between recognising the severity of the food allergy and being able to live with it. At the same time parents compared the food allergy with other types of allergies to emphasise the severity of the food allergy.

The relational aspects of risk and risk management

The second theme that comes through across the Scottish and Swedish data sets is the ways the parents see food allergy risk is managed in interaction between the child and others in a range of different everyday situations and local contexts.

The child's competence to manage allergy risk

The Swedish as well as the Scottish parents talked about their children's competence to manage food allergy risk as an individual skill that develops over time. But they also situated the child and her or his competence to be vigilant and avoid allergy risk *within* different situations and relations. As the only way to prevent food allergic reactions is to avoid the allergens, the 'dangerous' food stuff, children face challenges in a range of situations in

everyday life. The parents' accounts demonstrate how managing food allergy risk involves a complex interplay between the child, the food and other persons. Here a Swedish mother described how her daughter, allergic to milk-protein, now at the age of five had become more aware of the importance of informing others about her allergy:

Mother 1: There was a new staff member [at preschool] who gave her ice cream, so of course, she was so young and accepted what they gave her, and then had a reaction immediately.

Mother 2: But now she knows herself.

Mother 1: Now she knows herself, she is very good at not accepting anything she has not had before, and asks me can I have this if there is something new, if we are in a new place….

Father 1: Klara does the same.

Mother 1: Yes, they do get very good at it, when she plays with her doll, the doll reads the ingredients, so they do get used to it. (Focus group, Sweden)

Similarly, a Scottish mother argued that the competence of children to be aware of and manage food allergy risk develops with age. When her thirteen year old son was younger, he did not fully understand the severity of his allergy, but now he is more cautious. For example when he goes to the movies with his friends, and must be vigilant and not eat candy with nuts. Even if this mother regards her son to be 'quite sensible' she also recognised that in some situations he might just 'go for it' to avoid the social risk of not being like everybody else, also indicating that his competence is embedded in the specific situations and in the interaction with the people involved. The parents' accounts also show how the children have

to learn how to manage the adrenaline injector, but also how this competence comes into play in specific situations and might amount to social risks. The children have to practice how to administer the injector to be able to use it in real-life situations, not least because there can be long periods between allergic reactions. It can even be 'once in a lifetime you use an adrenaline auto injector', as a parent commented when comparing food allergy management to diabetes management (Scottish workshop). To be able to respond to a reaction, the injector has to be at hand and the young person prepared to use it.

> Now he knows himself how to deal with the medicine, he has seen a very good doctor at the hospital and has finally learned how to, or at least done the injection once or so, and that is in a way our security, but then, a fourteen year old forgets things, and he will be in one place and the medicine in another, that's how it is. (Individual interview, Sweden)

Even if the young person knows how to administer the injector, actually using it in an acute situation can be challenging. In addition, the bodily experience at the very moment of the allergic reaction can be of importance:

> What he's always said was when it starts to happen he feels out of control because he knows quite quickly that he's going to go to sleep, and when he wakes up it's all happening to him (Individual interview, Scotland).

Further, the design and size of the injector can pose specific challenges and a hassle in everyday life:

> if it was something that could slip into his wallet or something that, you know, slipped on to the side of his mobile phone, something like that […] I think it

> definitely has to do with how portable it is […] And another thing is he changes jackets, he always has one in his blazer pocket, it's zipped up inside of his blazer pocket, that's fine, that's always there. But other ones, he changes clothes, you find it lying beside the bed and I think that is the problem with it. (Individual interview, Scotland)

These examples show how the management of the adrenaline injector is not constructed just as an individual task, something that the child must learn to master. Rather it is the encounter between the individual child, the medical device and its properties *and* the demands of everyday life that comes to the fore.

Here, we see that the parents affirm the idea that the children themselves are involved in a learning process that amounts to a growing capacity to manage their food allergy but also that the risk of an allergic reaction emerges in interaction with others who are not so knowledgeable. This notion of a learning process raises questions about how local health care resources are utilised by parents and children. It is noteworthy that Scottish parents referred to the Anaphylaxis Campaign when they talked about how they should communicate allergy risk to their children or how their children could benefit from taking part in workshops that the Anaphylaxis Campaign arranges. The Swedish parents, on the other hand, seldom mentioned the Swedish Asthma and Allergy Association. Several of the Swedish parents who took part in focus group also mentioned that they appreciated sharing their experiences with other parents of children with food allergy. Thus, it seems like the Anaphylaxis Campaign is an important part of the Scottish parents' local framework (which however could be due to more explicit questions being asked), although we have not explored how the parents identify or use resources from the Campaign. The Swedish case is

more unclear, but there seems to be a need for more arenas for parents to meet and discuss their children's food allergies.

Risk management in local contexts

Also, parents' accounts show how they oscillate between on the one hand emphasising the child's understanding or behaviour as the most significant risk aspect and on the other hand a focus on risk as related to specific situations or contexts. This movement back and forth varies across data sets and within and between interviews and is related to how parents view the particular situation, as well as how they regard the child's capability to manage risk. In the following quote, a Swedish mother suggested that her daughter's participation in activities at the school leisure centre involves allergy risks:

Mother 3: She [daughter allergic to milk protein] reads the labels herself, and even finds out things herself at the school leisure centre, like when they were going to barbecue hamburgers, and she didn't recognise the package, and she read the text and asks the staff what is whey [whey contains milk-protein], no they don't know, and like start asking each other, but she feels somehow,

Mother 1: She sort of didn't recognise?

Mother 3: Instead of calling to ask me, because I said it is better you call once too often, she chooses to say she is not hungry, and that's right, as I told her, you are allergic to whey, I have prepare a file for the school leisure centre where it says what it means to be allergic to these food stuffs and what will happen in the body, and why and what she cannot eat and what she can eat, I have included pictures of the food product that they can buy, and this file is supposed to follow her, and still, when they bring together groups [of children] at the centre

> or when they are in a different place and have different staff, they don't bring the file.
>
> (Focus group, Sweden)

In this case, it is the failure in the school routines that poses a risk to her daughter. The daughter is depicted as a competent risk manager who knows how to avoid the dangerous food but at the same time portrayed as being in a vulnerable position and not fully able to address her own needs. Like this mother, other parents described that they go through considerable efforts to inform school staff about their children's allergies to make school a safe place, but everyday life situations still involve risky moments which are hard to foresee. As one Scottish mother put it, she trusts her son's competence to manage his food allergy but yet there remains uncertainty: 'it's been really easy because of his personality and everything and he's sensible, he'll maybe have an off day sometime I don't know '(Individual interview, Scotland).

In the next excerpt a father of two nut-allergic teenagers portrayed a rather complex picture of peers as both a component of the protective system around the child *and* a potential risk:

> My fear would be really as they get older they'll start going out with friends, going out to pubs and things like that, probably the lack of understanding of others more than anything else, the severity of it. I don't think either of them would put themselves in a situation where they're you know, they would sort of, I don't know get wrecked and decide to risk something, to take a risk //My fear would be others and the sort of peer pressure they would put on them on or one of them sort of decides to spike something or doesn't think, you know

> they think let's throw a peanut into their food and see what happens, things like that worry me. But having said that so far, you know certainly with Mike his friends have been fairly understanding, they all know about it and Mike is quite happy to tell them all about it. I would hope that they would sort of look out for him if he were in a situation like that. (Individual interview, Scotland)

This father emphasised that he trusts his children but is worried that other teenagers, who do not really understand the severity of the allergy, might act recklessly. At the same time, he regards his son's friends as being supportive and hopes that they would look after him in a dangerous situation. Similar to other parents, this father recognised that children with food allergy not only have to manage health risks when trying to avoid allergens or take medication, but also have to deal with the 'social risks' of being seen as different. Parents reported that when taking their medication young people face social risks of being a 'bit un-cool' or of being seen as different from their peers. But other people can also be a support in managing the food allergy. A Scottish mother recognised that friends of allergic children can be safeguards in the case of a severe reaction in the following interview extract:

> I think teenagers would, they wouldn't have any problems doing it [administer adrenaline], some of them don't like the size of the needle but they have practised with the practice pen or on an orange with an old injector. I would, I feel happier if she's with kids that know. (Individual interview, Scotland)

The dependence on others in case of an allergic reaction when the injector is needed is prominent in the parents' accounts. A Swedish mother described that her son had left school

when he experienced a reaction, called his parents, and how she then found him at home with the adrenaline auto injector in his hand:

> I don't know how to get home fast enough, and when I come home he sits there holding the injector, and has taken off all his clothes, and is completely gone, then he takes the injector, and I talk to him at the same time, and by then we have called the ambulance (Focus groups, Sweden)

This mother argued that you should not be alone in case of a severe reaction, and that it would have been better if her son had stayed at school when he began to feel ill.

What we see in this study is that given the nature of the allergy risk, the high stakes and uncertainty, and the various risk management strategies described by the parents – such as making children aware of allergy risk, educating school staff, efforts to safeguard the child's environment – the analysis of the datasets shows us how the food allergy demands constant vigilance by parents as well as the child. This vigilance is characterised by having to take place within a relational field of interaction with others, in a variety of places where the child spends time. Importantly, these places cannot be checked and watched over once and for all. On the contrary, the risk may vary within the very same space from day to day and from moment to moment and is dependent on several actors, even within the specific school or network of friends. This means that different environments can be more or less stable in this respect, for example if all staff at school have been informed about the child's food allergy (or just the school nurse), or if the child's friends know about the allergy and how to administer adrenaline in case of an allergic reaction (or just the best friend). Allergy risk is in this sense in constant flux.

The parents in this study acknowledged the competence of their children to manage food allergy risk, growing with age. At the same time they are aware of the ways the child at any time can be exposed to allergy risk in different situations together with others. Risk can emerge in interaction with others, but the child can also be helped by others. The management of food allergy risk can thus be seen as a constantly ongoing process where risk *and* safety can be understood as related to each other in the dynamics of interaction with others in everyday life.

Discussion

Food safety is generally taken for granted, but in sharp contrast to studies that demonstrate how people bracket out food risks in their everyday life (Green et al. 2003; Hawkes et al 2009; Fisher and De Vries 2008) in this article we have shown how food allergy elicits a different response. Our findings are based on secondary analysis and are limited in scope to the time and the range of various local contexts of the original studies that constitute the basis for this analysis. However, our findings do demonstrate some clear similarities across the different socio-cultural contexts in the Swedish and Scottish data, similarities that indicates a more general response to food allergy risk.

Firstly, food allergy is depicted as a condition which involves a 'death risk'; the life-threatening aspect of food allergy. The analysis supports earlier findings that child food allergy involves an existential dimension of a life-threatening risk, always lurking in the background. An earlier analysis of the Swedish data (Stjerna et al., 2014) showed that despite varying risk management strategies 'the ultimate risk of a severe reaction' seemed 'to remain a fundamental condition in parent's lives' (p. 142). Similarly, Gallagher et al. (2016) found an uncertainty as to 'where or when a reaction will strike' and 'the possibility of death in unlikely spaces, a spectre hovering in the background' (p. 440) in a study of teenagers' experiences of being at risk of anaphylaxis. Other researchers have pointed out that generally speaking, risk constructions imply adverse consequences and this harm or danger threatens some kind of explicit or implicit value of an object at risk (Boholm & Corvellec, 2011). We found that the life-threatening aspect is undeniably related to the individual child; it is her health and ultimately her life that is at stake here. Thus, this life threatening aspect of food allergy seems to be fundamental to parents' understandings of

the allergy per se, and to the ways they reflect on the management of risk, more or less always present across different local contexts. This is also in line with research about parents' experiences of caring for children with potentially life-threatening conditions other than food allergy. For example, parents of children with type 1 diabetes, aged 4-17, depicted themselves as always 'hyper-vigilant', unable to switch off the thoughts of their child's diabetes, regardless of the child's age or ability to self-care (Marshall et al., 2008).

Second, this understanding of food allergy risk as a 'death threat' seems to be an ever present backdrop to the ways parents talk about allergy risk management in everyday life. Our analysis shows that parents expect their children to manage their food allergy more independently as they get older, and in this sense see food allergy management as an individual skill. But at the same time food allergy risk is seen as a relational phenomenon, meaning that the risk per se – health risks in contact with dangerous foods and in responding to severe allergic reactions as well as social risks – emerges in the interaction between the young person's individual competence to manage allergy risk and the understandings and behaviour of others. Also, within these interactions, social aspects of risk management become crucial, anchored in a variety of local settings in time and space.

There is no doubt that young people with food allergy face social risks when managing their food allergy, also seen in other studies (DunnGalvin et al., 2009; Fenton et al., 2013; Stjerna, 2015) The assumption that young people with chronic illness are striving to 'pass as normal' in context where they spend time with their peers is a dominant theme in the literature (see Lambert & Keogh, 2015; Balfe 2007). However, the parents' accounts demonstrated that although the child found it embarrassing to administer adrenaline in some situations, the design of the adrenaline autoinjector *and* the fact that the body is inflicted by an allergic

reaction (dizziness, sweating or even passing out), also influence the child's agency in such situations. Thus, to further our understanding of 'situated risk' we have to take into account that people's dependence on medical devices is played out in different local contexts mostly not constructed for the disabled body (Hansen & Philo, 2007), and also influenced by the design of the aid per se. Bringing the adrenaline auto-injector into human interaction together with the bodily experience of an allergic reaction adds to the complexity of the object of risk. Our analysis demonstrates how challenging it can be to respond to an allergic reaction, managing the body's reactions to allergens *and* a medical device, as well as being dependent on others in this precarious situation.

This is also in line with the findings of researchers who have shown how the risk experience of young people with food allergy or the parents' understanding of the young person's risk experiences, varies between different social contexts and places (DunnGalvin et al., 2009; Stjerna et al., 2014; Stjerna, 2015; Fenton et al., 2011; Fenton et al., 2013). Furthermore, as pointed out by Rous and Hunt (2004), the management of food allergy at school involves certain dilemmas such as caring for but not stigmatising the young allergic person as well as a division of responsibility between different actors. This relational understanding of risk and a risk in flux, brings to the fore the ways the individual child is dependent on the possibilities to foresee and avoid allergy risk in the variety of situations in everyday life, at home and school and all other places where the child spends time, with or without adults. The possibility of preventing food allergy risk can be thus be seen as more than an individual skill. The understanding of risk as a relational as well as context-bound in this sense seems to be fluid and ever changing, across different contexts. Thus, to better understand the challenges the child faces when managing allergy risk, there is a need to shift focus from the individual child to a closer examination of the 'risk management conditions' prevailing in actual

everyday situations. Importantly, these patterns in how parents see the child's allergy risk management cannot be linked to either Swedish *or* Scottish parents but emerge across the datasets. The question of *how* variations within the data sets are linked to local contexts and local resources within and across the two countries would however need to be explored more in depth to further our understanding of the impact of 'the local' in food allergy risk management.

Finally, another potential area to explore in more detail is how parents communicate and negotiate food allergy risk to their children: a more fine-grained analysis focusing on a few cases/interviews from this comprehensive material may allow for differences at a more discursive level to emerge. There is a tension in how parents on the one hand have to encourage their children to be constantly aware of food allergy risk and on the other hand develop trust in their children as risk managers and let them live as normal lives as possible. Earlier research has indicated that parenting a child with food allergy inevitably means that you have to put your trust in others, individuals as well as institutions such as day care, schools and health care. This means that risk and trust can be seen as closely related in the management of food allergy but the issue of 'trust' has so far received limited attention, not only in studies of food allergy, but more widely in research of children, risk, safety and danger in the everyday context of family life (see e.g. Harden & Backett-Milburn, 2008).

Giddens' (1991) idea that trust in others will contribute to a sense of ontological security, as it will help to shut out risk and to move on with life, is also relevant in this case. However, unlike threats that are more distant and imagined, such as shocking news presented in the media about a new disease, living with food allergy entails a threat that is immediate, experienced, enduring and ongoing in the lives of those affected. We would argue that food

allergy produces uncertainty and a need for control that has to be negotiated within social relations on a daily basis across different local contexts, here and now as well as in the future. Also, the character of the potential risk, the life and death aspect, makes the issue of trust in others even more critical. For example, parents can trust a 'good' doctor or a teacher who is engaged with their child, which is in line with the reasoning of Alaszewski and Coxon (2009) about trust in everyday life as embeddedness 'in personal relations and communications so that when people encounter abstract expert systems such as medicine they judge them in terms of the person who is the representative of that system' (page 204). Also, children's and young people's networks and close friends are identified as (trusted) safeguards to children with food allergy. But, at the same time, the normally vigilant child can have a 'day off' or the usual teacher can be on leave. In other words, continuous efforts are needed to see to that the child is safe. However, we would suggest that in the case of living with an illness that produces everlasting insecurity and need for constant vigilance, the 'protective cocoon' built by trust in others, the child, institutions, family and friends (Giddens 1991, p. 196) might be more fragile compared to dealing with more 'distant' risks. In the case of food allergy, the risk is in play daily in a variety of contexts, and it is hard to foresee everything that could impel risks to emerge.

Conclusion

In the wider context of neoliberal biopower in the Western world the food allergic individual is urged to take control over her allergy by adrenaline autoinjector carriage, allergen avoidance and so forth rather than challenging structures that make certain spaces risky to those with food allergies (Gallagher et al., 2016). However, in this article we have shown that parents situate individual strategies in a context and in a relational network of human and

material objects. It draws attention to the context as well as risk as a situated phenomenon. Prominent is that when parents reflect on the risks their child with food allergy may face in daily life, they do not focus solely on the child's competence as a risk manager. Instead they recognise that if food allergy risk management is to be successful, this endeavour necessarily involves several parties, such as teachers and peers. Risk management is in this sense a social project, located to different spaces and carried out *through* social interaction; that is in dialogue with others to make them understand the risks involved and perform according to the norm of vigilance. This understanding contradicts the idea of the rational atomised risk manager (Zinn, 2009) and supports the relational aspect of risk and risk management in everyday life. We would therefore argue that food allergy is an example of a wider social issue that deals with ideas about ability and disability, that also has implications in term of how different places are designed, materially as well as socially.

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Table 1: Swedish and Scottish data sets

	Focus groups	Workshops	Individual Interviews	Couple Interviews
Swedish material	10		7	
Scottish material	1	2	24	4
Total	11	2	31	4

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